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EXPLORING THE CHALLENGES OF ACCESSING MEDICATION FOR PATIENTS WITH CYSTIC FIBROSIS

Journal:	*Thorax*
Manuscript ID	thoraxjnl-2021-217140.R2
Article Type:	Brief communication
Date Submitted by the Author:	02-Aug-2021
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Keywords:	Cystic Fibrosis, Psychology, Respiratory Infection

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SH, NR, SS, AS were involved in concept, design, data collection, analysis and preparing the final manuscript. PW and ZE involved in the data collection, analysis and preparing the final manuscript, PL involved in analysis and preparing the final manuscript. AJAD involved in preparing the final manuscript.

Keywords: Cystic fibrosis, medication, treatment burden

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Acknowledgements: This work was funded by the UK Cystic Fibrosis Trust, and the University of Nottingham. N Rowbotham was an NIHR Academic Clinical Fellow at University of Nottingham. A Smyth is part of the National Institute for Health Research Nottingham Biomedical Research Centre

Ethical Approval: Faculty of Medicine & Health Sciences Research Ethics Committee deemed this work not to require ethical approval on 30/4/2019.

Abbreviations: CF: Cystic Fibrosis; CFTR: Cystic Fibrosis Transmembrane Conductance Regulator; GP: General Practitioner (Primary Care Doctor); JLA: James Lind Alliance; MDT: Multi-disciplinary Team; PSP: Priority Setting Partnership; PwCF: people with CF.

Abstract (99 words)

Reducing treatment burden in cystic fibrosis (CF) is the top research priority for patients and clinicians. Difficulty accessing medication is one aspect of treatment burden. We investigated this with an online survey available globally for CF patients and health care professionals. Almost three quarters of CF patients in our survey report difficulty getting repeat prescriptions on time and most community pharmacists experience interrupted supplies of CF specific medications. These barriers affect emotional and physical health of people with CF. Two thirds of people with CF would like to get all their CF medication from one place, their CF centre.

Introduction

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Reducing treatment burden for patients with CF was voted the number one research priority by people with CF (pwCF), their parents/carers and healthcare professionals in a James Lind Alliance Priority Setting Partnership. (1) 'Treatment burden' describes the increased workload associated with health care affecting individuals' physical and psychological wellbeing (2). The James Lind CF2 project further explored this research priority.

CF is a multisystem disease requiring complex treatment including specialist medications (e.g. inhaled antibiotics and CFTR modulators) and non-specialist drugs (e.g. bronchodilators and multivitamins), the latter being drugs which are used almost exclusively in the treatment of pwCF which are usually prescribed by the CF team. High treatment burden is common to many chronic diseases, resulting in reduced adherence, wasted medication, health deterioration and poorer quality of life. (3)(4) Treatment burden for pwCF is considerable – most spend around two hours per day on treatment. (5) Accessing prescribed medications is an issue for patients with chronic diseases which contributes to treatment burden. (6) We aimed to review the obstacles pwCF encounter when accessing medications and to demonstrate insight from professionals who provide medications (pharmacists and primary care doctors).

Methods

The James Lind CF2 project explores in depth some of the research priorities identified by the James Lind Alliance priority setting partnership for CF. (1) It is supported by the UK National Institute for Health Research (NIHR) and the UK CF Trust. An online survey for pwCF was conducted generating free-text data on accessing medications (5). A further survey for primary care doctors and community pharmacists (with guidance from a focus group) was distributed using SurveyMonkey™ and was available for 4 weeks in June 2019. Both

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quantitative ‘single answer’ and qualitative ‘free text’ questions were incorporated. A final questionnaire to pwCF (July 2019) asked; ‘should all medication be accessed from secondary care?’.

The questionnaires were not country-restricted and were promoted via social media. They were anonymous; no personal data were stored, or financial incentive given. All responses to the questionnaires were non-compulsory. Data were downloaded into Excel for quantitative analysis and into NVivo for qualitative analysis. Prior to commencing this work we published our protocol at:

https://nottingham-repository.worktribe.com/output/2226944

Results

James Lind CF2 question “Do you ever have difficulties getting the medications you need from your GP/Pharmacist/hospital/homecare?” found 76% (241/317) of pwCF had difficulty accessing medication (5). The demographics of the participants have previously been published (5). Of the pwCF who had difficulty accessing medication, 65 participants expanded with a free text response following on from the quantitative question. Six recurring themes were identified. (Figure 1) Emotive language was used in free-text responses describing challenges that pwCF experienced in accessing their medication (Figure 2).

The healthcare professionals’ survey yielded 256 responses, including 249 from the UK. Almost a third of respondents did not have pwCF in their cohort (31%; 78/249), with the majority having one or two pwCF 45% (114/249). Primary care doctors accounted for 16% of

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the responses (40/249). Data on prescribing revealed that 39% (13/33) lacked confidence when prescribing CF specialist medication and 50% (17/34) had been asked to prescribe medication that should be prescribed by secondary care. Suggestions on how the CF centre can support primary care included education, ensuring up-to-date guidelines and having access to discuss care. Many pwCF did not see value from primary care doctors' input, and some primary care doctors felt that their role was 'limited as there is such good access to specialists'. However, others perceived their role to be caring for the pwCF outside of the CF condition, *'including mental health, contraception, and vaccinations'*.

Community pharmacists describe their role as a medication dispenser to ensure continuous treatment and optimising adherence. Difficulties obtaining medication supplies are reported by 55% (52/94) of community pharmacists including: pancreatic enzyme replacement therapy; dornase alfa; CF specific vitamin preparations; and colistimethate sodium. '*Supply problems are a major issue, this is not a pharmacy problem but industrial pharmaceutical companies causing the delay'*. Some specialist medications have a quota restricting supply, '*for example a manufacturer restricts supply to 2 per month, but you have a script for 12*'. Expensive medications with short shelf-lives are not kept in stock because of the potential for waste if treatment is changed. For routine repeat-prescriptions, 48% (95/196) of pharmacies require 1-2 days' notice. For specialist medication 39% (75/196) of pharmacies require 3-4 days' notice with 10% (19/196) requiring 1-2 weeks' notice. Only 40% (76/192) of these have online repeat prescriptions requests.

PwCF and health care professionals were asked if all medication should be prescribed and accessed in secondary care (Figure 3). Overall, 65% (25/40) pwCF wanted to access

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medication from secondary care. Reservations included travel distance, car parking and hospital pharmacy delays.

Discussion

We present a complex process undertaken by pwCF to access medication, including 76% of those surveyed expressing difficulty getting repeat prescriptions from primary care. Our data suggest that this is part of the high treatment burden impacting upon physical and mental health.

Although each group interviewed has specific difficulties and frustrations, all are agreed on the need to simplify the process. Research shows that patients with chronic diseases have difficulty accessing medication, issues including pharmacy stock, medication errors and short durations of prescriptions (7) – all issues raised in our study. This is exacerbated by the number of medications pwCF take (average 8 daily) (8).

Primary care doctors and community pharmacists describe the barriers to accessing medication including practitioners' lack of familiarity with specialist medication and interrupted supplies. A guide to improving the logistics of obtaining medicines in the community offers pwCF and their families, practical suggestions on how to reduce such difficulties (9). Primary care doctors suggested that better communication with the CF centre and accessible guidelines would support their prescribing. The UK National Health Service (NHS) long-term plan (2019) aims for electronic prescribing (10) which may improve communication between the CF centre and primary care.

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Our study has limitations. Respondents were self-selected and those with negative experiences might be more motivated to participate. We did not survey CF centres. Not every respondent answered every question. The CF patient cohort responding to 'Should all medication be accessed from secondary care?' was a smaller group than the James Lind CF2 initial survey. We did not enquire as to whether a delivery service would aid access to medications. The surveys were conducted prior to the COVID-19 pandemic which might have altered responses, if patients were apprehensive about the infection risk in attending hospital. The strengths include the global reach and large number of responses to our original survey (941 responses from 21 countries) (1).

Conclusion

Accessing medication is a problem for pwCF adding to the high treatment burden, impacting upon both the emotional and physical health. The next step is for targeted quality improvement plans to help reduce treatment burden.

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Conflicts of interest:

AS reports a research grant and personal fees from Vertex. He has spoken at meetings supported by Teva and Novartis. These activities are outside the submitted work. In addition, Prof. Smyth has a patent *alkyl quinolones as biomarkers of pseudomonas aeruginosa infection and uses thereof issued*.

AD reports personal fees from Gilead, Chiesi, Novartis, ALK Abello and has attended dinners supported by Gilead and Chiesi, all outside the submitted work.

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Theme	Quotations
Short duration of medication dispensed 26% (17/65)	'They will only give 28 days supply of some of the items on prescription even when it's medicine that my daughter will be on for the rest of her life'
Perceived futility of primary care medication reviews 8% (5/65)	'An 8-weekly review [of medications] at hospital doesn't count', 'My medications are usually reviewed by the practice nurse [primary care] who has no experience of CF'
Delay in accessing acute medication 14% (9/65)	'It can be frustrating if we urgently need something that the local pharmacist doesn't routinely stock. Ciprofloxacin has been the classic case - as soon as a swab result is phoned in as requiring this specialised antibiotic, they don't have it in stock which means a trip to the hospital'
Difficulty in accessing a continuous supply of repeat prescription medication 49% (32/65)	'Often suppliers run out of medication and I have waited over 1 month for a nebuliser supply and went without it for that time.', 'Even after ordering a week in advance they [local pharmacy] don't always have everything we need', 'Usually I have an extra 2 weeks of stock to avoid complications when meds are unavailable.'
Primary care prescribing errors 26% (17/65)	'I am constantly chasing the GP [primary care doctor] because medications are not prescribed within the stated 48 hours, only partially prescribed, prescribed in the wrong form (for example liquid instead of capsules) or in the wrong dosage (especially Creon).'
Poor communication between primary, secondary care and the service user 34% (22/65)	'When the GP and hospital can't agree who will supply what, [*it is*] annoying', 'Sometimes the GP doesn't update the prescription after the instructions from the hospital. It takes time to chase up and sort out'

Figure 1. Quotations from pwCF and their families for each theme identified. GP= General Practitioner (Primary care doctor)

189x178mm (157 x 157 DPI)

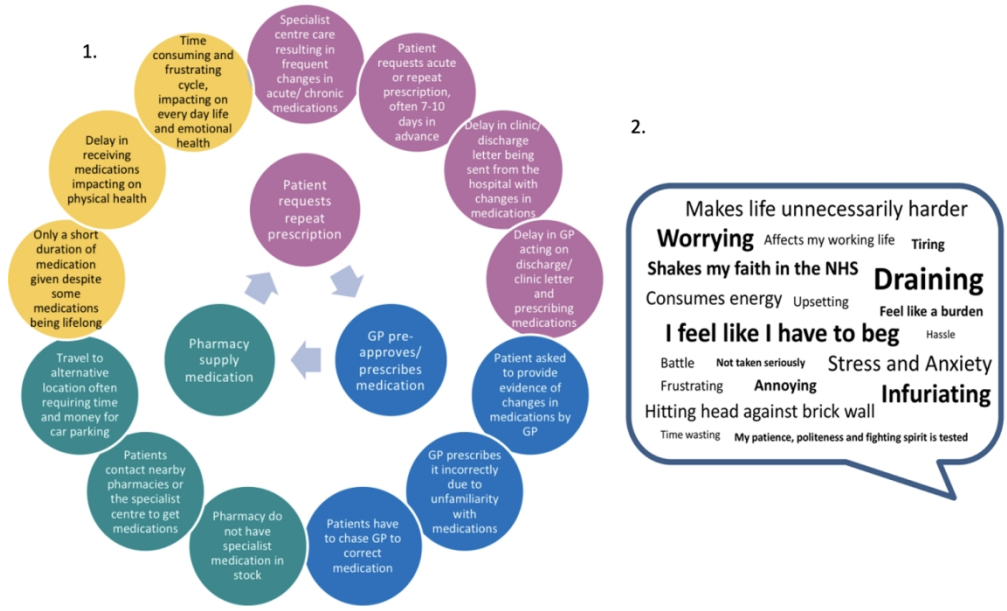

Figure 2. 1. Inner flow chart depicts the journey to accessing medications where the patient does not have a chronic, multisystem disease. The outer circle is a pathway described by the CF patient group that they take to access medications 2. Emotive language used by the patient group to describe the cycle in 1.

97x62mm (400 x 400 DPI)

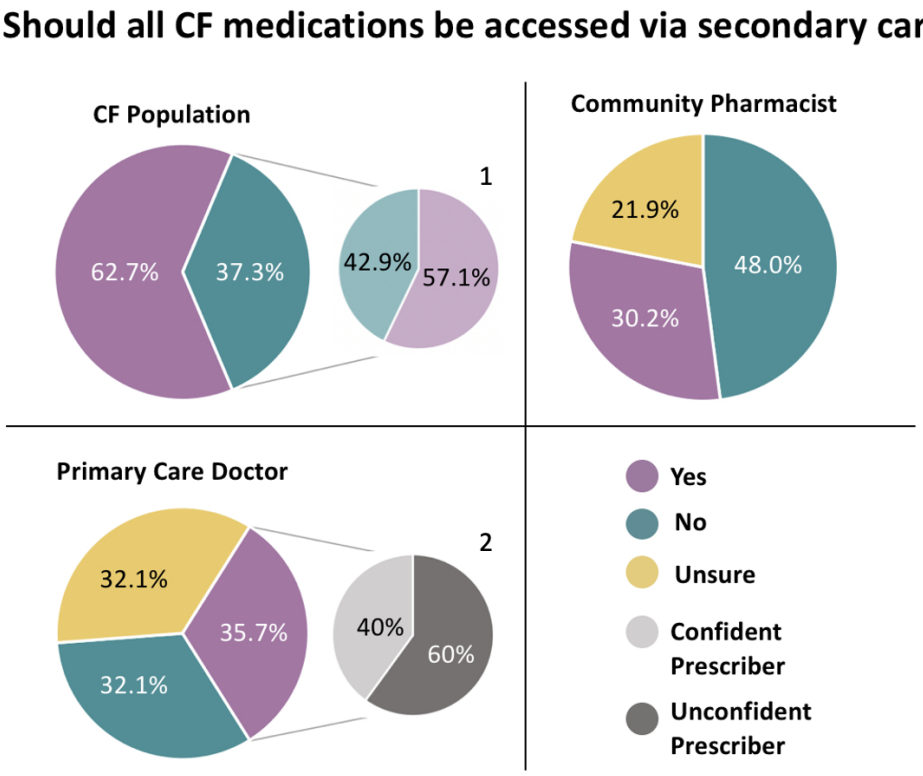

Figure 3. Should all medications be accessed from secondary care? Responses from the CF population, Community pharmacists and primary care. 1. For those that answered 'No' if travel was not an issue, would they change their mind? 2. For primary care doctors who said 'No', how many were confident at prescribing

73x59mm (400 x 400 DPI)